

## Frequently Asked Questions about Lupus

### What is lupus?

Lupus, also called systemic lupus erythematosus (sis-teh-mik lew-pus er-eh-thee-muh-toh-sis) or SLE, is a disease that affects your immune system. Normally, your immune system fights infections caused by germs. Instead of protecting your body, your immune system makes the mistake of attacking your body's healthy cells. Lupus can affect almost any part of your body, including your joints, skin, kidneys, heart, lungs, blood vessels, and brain. There is no way to know what part of your body will be affected. For most people though, lupus is a mild disease affecting only a few parts of your body, and some patients don't get inner organ problems (like in the heart and lungs), but do have skin and joint problems. Normally, lupus develops slowly, with symptoms that come and go. For some, it can cause serious and even life-threatening problems. Even for patients with diseases that hurt their organs, with good care and management and a strong partnership between a patient and her health care provider, the prognosis is good.

### Who has lupus?

Lupus affects up to 1.4 million people in the United States. About 9 out of 10 people who have lupus are women. Lupus is 3 times more common in black women than in white women. It is also more common in women of Hispanic/Latina, Asian, and American Indian descent. Black and Hispanic/Latina women tend to develop symptoms at an earlier age than other women. African Americans have more severe organ problems, especially with their kidneys.

### What are the different types of lupus?

There are several forms of lupus:

**Systemic lupus erythematosus (SLE).** SLE is the most common type of lupus. SLE can affect many parts of the body including joints, skin, kidneys, lungs, heart, blood vessels, nervous system, blood, and brain. Although SLE usually develops in people between the ages of 15 and 44 years, it can occur in childhood or later in life. The signs of SLE vary and there are usually periods of both illness and wellness (also called remission or having no symptoms). Some people have just a few signs of the disease while others have more. Its symptoms can include:

- "butterfly" rash across the nose and cheeks
- skin rashes on parts of the body exposed to the sun
- sores in the mouth or nose
- painful or swollen joints

- fever
- weight loss
- hair loss
- fatigue
- chest pain when taking deep breaths
- purple or pale fingers or toes from cold or stress
- abdominal pain
- kidney inflammation
- headaches
- paranoia
- schizophrenia
- hallucinations
- depression
- trouble thinking
- memory problems
- seizures
- strokes
- blood clots

**Discoid (diss-koid) lupus erythematosus (DLE).** DLE just affects the skin. It does not affect other organs, like SLE. Its symptoms can include:

- a red, raised rash on the face, scalp, or other parts of the body. The rash may become thick and scaly and may last for days or years.

- sores in the mouth or nose (sometimes)

A small group of people with DLE later develop SLE. There is no way to know if someone with DLE will get SLE. A skin biopsy (removing a piece of skin to look at under a microscope) of the rash is taken to diagnose this type of lupus.

**Drug-induced lupus.** This type of lupus is a reaction to some prescription medicines. The symptoms of this type of lupus are similar to SLE, except you don't have problems with your kidneys or central nervous system. It can take months to years of taking the medicine before symptoms appear. After you stop taking the drug, it could take days, weeks, or months for symptoms to go away.

**Neonatal lupus.** While rare, some newborn babies of women with SLE or other immune system disorders get lupus. Babies with neonatal lupus may have a serious heart defect. About one-half of babies with neonatal lupus are born with a heart condition. This condition is permanent, but it can be treated with a pacemaker (a device that helps the heart set a rhythm). Other affected babies may have a skin rash or liver problems. Some babies have both heart and skin problems.

## What causes lupus?

The cause of lupus is not known. It is likely that there is no single cause but a combination of genetic, environmental, and possibly hormonal factors that work together to cause the disease. Lupus is not contagious—you can't catch it from someone. No specific "lupus gene" has been found, but it does run in families.

## How is SLE diagnosed?

SLE may be hard to diagnose and is often mistaken for other diseases. For this reason, lupus has often been called the "great imitator." No single test can tell if a person has lupus. There are many ways to diagnose SLE:

1. **Medical history.** Give your health care provider (HCP) a complete, accurate medical history. This information, along with a physical exam and special tests, helps your HCP rule out other diseases that can be confused with lupus.
2. **Symptoms.** Having 4 (or more) of the 11 symptoms of lupus, as defined by the American College of Rheumatology. For a list of these symptoms, go to [www.rheumatology.org/research/classification/sle.html](http://www.rheumatology.org/research/classification/sle.html).
3. **Lab tests.** The Antinuclear antibody (ANA) test is a commonly used test. An antibody is a chemical the body makes to fight off infections. The test looks for the strength of your antibodies. Most people with lupus test positive for ANA. However, other health problems, like malaria (a disease from a mosquito bite), can also give you a positive test. That's why other tests may be needed.

## What are flares?

When symptoms appear, it's called a "flare." These signs may come and go. You may have swelling and rashes one week and no symptoms at all the next. You may find that your symptoms flare after you've been out in the sun or after a hard day at work.

Even if you take medicine for lupus, you may find that there are times when the symptoms become worse. Learning to recognize that a flare is coming can help you take steps to cope with it. Many people feel very tired or have pain, a rash, a fever, stomach discomfort, headache, or dizziness just before a flare.

Take steps to prevent flares:

- Learn to recognize that a flare is coming.
- Try to set realistic goals and priorities.
- Limit the time you spend in the sun.
- Maintain a healthy diet.
- Develop coping skills to help limit stress.
- Get enough rest and quiet.
- Exercise moderately when possible.
- Develop a support system by surrounding yourself with people you trust and feel comfortable with like family and friends.

## How is lupus treated?

There is no known cure for lupus, but there are effective treatments. Most of the symptoms of lupus are from inflammation (swelling), so treatment focuses on reducing the swelling.

Treatment may include taking these medicines:

- **Nonsteroidal anti-inflammatory drugs (NSAIDs).** NSAIDs are often used to reduce joint and muscle pain and inflammation in people who have mild SLE (pain isn't bad or organs aren't affected). There are many different types of NSAIDs, both prescription drugs and over-the-counter drugs. They include aspirin, ibuprofen, naproxen, and other medicines. Common side effects of NSAIDs can include stomach upset, heartburn, drowsiness, headache, and fluid retention. If you have any side effects, talk to your HCP. NSAIDs can also cause problems in your blood, liver, and kidneys. Stay in touch with your HCP to ensure these problems aren't happening to you.

- **Antimalarial drugs.** Medicines used to prevent or treat malaria are used to treat joint pain, skin rashes, and ulcers. Two common antimalarials are *hydroxychloroquine* (Plaquenil) and *chloroquine* (Aralen). Side effects of antimalarials can include stomach upset, nausea, vomiting, diarrhea, headache, dizziness, blurred vision, trouble sleeping, and itching.
- **Corticosteroid hormones.** These are powerful drugs that reduce inflammation in various tissues of the body. They can be taken by mouth, in creams applied to the skin, or by injection. Prednisone is a corticosteroid that is often used to treat lupus. Corticosteroids can have various side effects, so HCPs try to use the lowest dose possible. Short-term side effects include swelling, increased appetite, weight gain, and emotional ups and downs. These side effects generally stop when the drug is stopped. Long-term side effects of corticosteroids can include stretch marks on the skin, excessive hair growth, weakened or damaged bones, high blood pressure, damage to the arteries, high blood sugar, infections, and cataracts. People with lupus who are using corticosteroids should talk to their HCPs about taking calcium supplements, vitamin D, or other drugs to reduce the risk of osteoporosis (weakened, fragile bones).
- **Immunosuppressive agents/chemotherapy.** These agents are used in serious cases of lupus, when major organs are losing their ability to function. These drugs suppress the immune system to limit the damage to the organ. Examples are *azathioprine* (Imuran) and *cyclophosphamide* (Cytoxan). These drugs can cause serious side effects including nausea, vomiting, hair loss, bladder problems, decreased fertility, and increased risk of cancer and infection.

Work closely with your HCP to ensure that your treatment plan is as successful as possible. Because some treatments may cause harmful side effects, promptly report any new symptoms to your HCP. It is also important not to stop or change treatments without talking to your HCP first.

## Is it safe for me to become pregnant?

Today, most women with lupus can safely become pregnant. With proper medical care, you can lower the risks of pregnancy and deliver a normal, healthy baby. However, you must carefully plan your pregnancy. Your disease should be under control or in remission for 12 months before you get pregnant. Find an obstetrician (OB) who is experienced in managing high-risk pregnancies and who can work closely with your primary HCP. Plan your delivery at a hospital that can manage high-risk patients and provide the specialized care you and your baby may need. Talk to your doctor about which medicines are safe to take while pregnant.

Women with lupus may face certain problems during the pregnancy. While flares are not caused by pregnancy, flares that do develop often occur during the first or second trimester or during the first few months following delivery. Most flares are mild and easily treated with small doses of corticosteroids. Another complication is pre-eclampsia. If you develop this serious condition, you will have a sudden increase in blood pressure, protein in the urine, or both. This is a serious condition that requires immediate treatment, and you might have to deliver your infant early.

Babies born to women with lupus have no greater chance of birth defects or mental retardation than do babies born to women without lupus. As your pregnancy progresses, your OB will regularly check the baby's heartbeat and growth with sonograms (an machine that creates pictures of your baby's organs). Although giving birth to your baby early (prematurity) presents a danger to the baby, most problems can be successfully treated in a hospital that specializes in caring for premature newborns. About 3% of babies born to mothers with lupus will have neonatal lupus.

Breastfeeding your baby is safe for mothers with lupus. If you are on medications and breastfeeding, talk with your provider about how the medicine might affect your baby.

## **How can I tell the difference between symptoms of lupus and symptoms of pregnancy?**

It may be hard to tell the difference. You may have symptoms from being pregnant that you mistake for lupus symptoms. Here are just some problems that may cause confusion:

- **Skin.** While pregnant, you may have red palms and a rash. Lupus can also cause a rash.
- **Joints.** Lupus can cause arthritis, and pregnancy can cause aching in your joints.
- **Lungs.** It may be hard for you to breathe if you have lupus. Pregnancy can also cause a shortness of breath and hyperventilation.

Talk to your health care provider about how to tell the difference between the physical changes you will have during your pregnancy and symptoms of lupus.

## **How can I cope with the stress of having lupus?**

Staying healthy takes extra effort and care for women with lupus. Sometimes, women with lupus may feel tired, and you may need extra rest because of your treatments. If you feel tired, make a point to allow yourself extra time in your schedule for rest.

Some approaches that may help you to cope with lupus include:

- exercising
- relaxing using techniques like meditation
- setting priorities for spending time and energy
- educating yourself about the disease
- having a good support system

A support system may include family, friends, HCPs, community organizations, and organized support groups. Participating in a support group can provide emotional help, boost self-esteem and morale, and help develop or improve coping skills. Also, talk to your family about how they can support your efforts to take care of yourself.

## **What research is being done on lupus?**

There are many promising areas of research on lupus. Studies are looking at the safety of estrogen use (HT and birth control pills) by women with lupus; causes or risk factors for lupus (including behavior, genetics, environment, and culture); and lupus in minority women.

# The National Women's Health Information Center (NWHIC)

A Project of the Office on Women's Health in the U.S. Department of Health and Human Services

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## For more information...

For more information on lupus, call the National Women's Health Information Center (NWHIC) at 800-994-WOMAN or contact the following organizations:

### **National Heart, Lung, and Blood Institute (NHLBI)**

Phone Number(s): 301-592-8573

Internet: [www.nhlbi.nih.gov](http://www.nhlbi.nih.gov)

### **National Institute of Allergy and Infectious Diseases (NIAID)**

Phone Number(s): (301) 480-2814

Internet Address: [www.niaid.nih.gov/publications/autoimmune](http://www.niaid.nih.gov/publications/autoimmune)

### **National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)**

Phone Number(s): (301) 496-4484

Internet Address: [www.niams.nih.gov](http://www.niams.nih.gov)

### **National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)**

Phone Number(s): 800-860-8747

Internet: [www.niddk.nih.gov](http://www.niddk.nih.gov)

### **National Institute of Environmental Health Sciences (NIEHS)**

Phone Number(s): 301-496-3511

Internet: [www.niehs.nih.gov](http://www.niehs.nih.gov)

### **National Institute of Neurological Disorders and Stroke (NINDS)**

Phone Number(s): 800-352-9424

Internet: [www.ninds.nih.gov](http://www.ninds.nih.gov)

### **National Library of Medicine's MEDLINEplus**

Phone Number(s): (888) 346-3656

Internet Address: [www.nlm.nih.gov/medlineplus/lupus.html](http://www.nlm.nih.gov/medlineplus/lupus.html)

### **Office of Minority Health, Office of the Secretary**

Phone Number(s): (800) 444-6472

Internet Address: [www.omhrc.gov](http://www.omhrc.gov)

### **Alliance for Lupus Research**

Phone Number(s): 212-218-2840

Internet Address: [www.lupusresearch.org/](http://www.lupusresearch.org/)

### **American Autoimmune Related Diseases Association, Inc.**

Phone Number(s): (810) 776-3900 or (800) 598-4668 Literature Requests

Internet Address: [www.aarda.org](http://www.aarda.org)

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## **American College of Rheumatology**

Phone Number(s): (404) 633-3777

Internet Address: [www.rheumatology.org](http://www.rheumatology.org)

## **Arthritis Foundation**

Phone Number(s): 800-283-7800

Internet Address: [www.arthritis.org](http://www.arthritis.org)

## **Lupus Foundation of America**

Phone Number(s): (800) 558-0121

Internet Address: [www.lupus.org](http://www.lupus.org)

## **SLE Foundation**

Phone Number(s): 212-685-4118

Internet Address: [www.lupusny.org](http://www.lupusny.org)

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